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Parents' and patients' experiences with paediatric oncology care in Switzerland - satisfaction and some hurdles

Wangmo, Tenzin ; Ruhe, Katharina M ; Badarau, Domnita O ; Kühne, Thomas ; Niggli, Felix ; Elger, Bernice S ; Swiss Paediatric Oncology Group

Abstract: **QUESTIONS UNDER STUDY:** This paper explores parents' and patients' satisfaction with care in Swiss paediatric oncology settings and examines difficulties experienced while undergoing treatment for cancer. **METHODS:** Semistructured interviews were conducted with 19 parents, and with 17 children who were diagnosed with cancer and receiving treatment. During these interviews questions pertaining to communication and decision-making at time of diagnosis and throughout the illness course were asked. In this paper, we examined these interviews using thematic coding to identify themes with regard to satisfaction with care. **RESULTS:** Generally, participants reported being very content with the care they received. Aspects that contributed to satisfaction were the friendliness and responsive nature of healthcare staff; helpful communication; and professionals going beyond their duties to care for the family. In spite of mainly being pleased with the care they received, participants underlined several issues that made their experiences at times difficult. These included frequent change of physician or receiving care from another unit, which for them represented lack of continuity of care; language problems; and challenges with reproductive health issues of the child. Additionally, patients suggested several ways to improve hospital stays and thereby patient satisfaction. **CONCLUSION:** Participants reported being very satisfied with care delivered by paediatric oncology units. Nevertheless, they also identified problems that are worth addressing in order to efficiently tend to the needs of patients and families undergoing this difficult experience. Future research is needed to explore how care for children with cancer and their families can be further improved.

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Parents' and patients' experiences with paediatric oncology care in Switzerland – satisfaction and some hurdles

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Summary

QUESTIONS UNDER STUDY: This paper explores parents' and patients' satisfaction with care in Swiss paediatric oncology settings and examines difficulties experienced while undergoing treatment for cancer.

METHODS: Semistructured interviews were conducted with 19 parents, and with 17 children who were diagnosed with cancer and receiving treatment. During these interviews questions pertaining to communication and decision-making at time of diagnosis and throughout the illness course were asked. In this paper, we examined these interviews using thematic coding to identify themes with regard to satisfaction with care.

RESULTS: Generally, participants reported being very content with the care they received. Aspects that contributed to satisfaction were the friendliness and responsive nature of healthcare staff; helpful communication; and professionals going beyond their duties to care for the family. In spite of mainly being pleased with the care they received, participants underlined several issues that made their experiences at times difficult. These included frequent change of physician or receiving care from another unit, which for them represented lack of continuity of care; language problems; and challenges with reproductive health issues of the child. Additionally, patients suggested several ways to improve hospital stays and thereby patient satisfaction.

CONCLUSION: Participants reported being very satisfied with care delivered by paediatric oncology units. Nevertheless, they also identified problems that are worth addressing in order to efficiently tend to the needs of patients and families undergoing this difficult experience. Future research is needed to explore how care for children with cancer and their families can be further improved.

Key words: paediatric oncology; satisfaction; care; parents; children

Introduction

A child's cancer diagnosis is a catastrophic event for the entire family, resulting in considerable emotional turmoil [1]. Although children with cancer have high chances of cure [2–5], a cancer diagnosis is still associated with morbidity and death, leading to feelings of fear, devastation, or loneliness [6, 7]. At the same time, patients and parents immediately find themselves facing high-intensity treatment [8]. This situation puts numerous strains on the child as well as the family and can be associated with loss of a sense of normality as lives are disrupted [1, 9]. In these difficult and challenging circumstances, both emotional support (e.g., guidance, sense of friendship) and practical help (e.g., flexible scheduling, help with financial matters) from interdisciplinary oncology staff members represent important resources for families [1, 10]. Parents report the social competence of doctors, nurses, and other healthcare professionals (e.g., social workers, psychologists, psychotherapists, physiotherapists) as one aspect of good quality of care [2, 11]. This interpersonal aspect of healthcare is, among others, considered to be a component of patient satisfaction [12, 13].

In the literature, other facets of care that are considered critical for patient satisfaction are accessibility to clinics and services, technical quality of care, and provision of information to patients [13]. Patient satisfaction is an important therapeutic concern because it is associated with less distress, better coping and compliance, and increased quality of life [14, 15]. Hence, patient satisfaction measures can be of use in improving quality of healthcare delivery and its performance [13]. However, the concept has so far received little attention in paediatric oncology [16] with a few exceptions that include the quality of paediatric palliative and end-of-life care [3, 17].

Three decades ago, Barbarin and Chesler [18] found that parents of children diagnosed with cancer appreciate physician attributes such as sympathy, warmth, attention, and

empathy. More than a decade later, Varni, Quiggen, and Guadelupe [16] developed the Pediatric Hematology/Oncology Parent Satisfaction Survey to assess parents' satisfaction with healthcare. Their tool included four domains of satisfaction: (a) general, (b) with staff, (c) with the amount and timing of information, and (d) with provision of emotional support by staff. They reported parents' high degree of contentment with healthcare but acknowledged the limitations of their questionnaire, which did not permit an insight into how patients themselves perceive quality of care. In the Swiss context, a quantitative study assessed satisfaction with follow-up healthcare among paediatric cancer survivors and concluded that this group was very satisfied with the care received [19, 20]. In light of the scarcity of research on families' and patients' views on the quality of care in paediatric oncology during the intensive treatment phase, we qualitatively explored parents' and patients' satisfaction with care, as well as difficulties they identified when undergoing cancer treatment in Switzerland. Based on the literature presented above, in this paper we use satisfaction to mean patients' and their parents' positive evaluation of the quality of care received during their treatment in the paediatric oncology setting. Such a study is relevant because it highlights the voices and experiences of the patients and families who are less researched and known to healthcare providers. This paper adds important information that could help to understand the care provision dynamics in paediatric oncology in Switzerland and improve certain aspects of the care setting resulting in higher satisfaction.

Methods

We chose a qualitative research methodology because it facilitates understanding of behaviour in everyday contexts and exploration of individual perspectives, particularly subjective understanding of complex concepts such as health and quality of care, but also intrinsically personal states such as being a patient. Although this type of research is often criticised for being anecdotal and not generalisable, it contributes important knowledge by investigating personal beliefs, attitudes, and experiences, which are often not easily accessible by quantitative methods [21]. Data for this study come from a larger project that employed both qualitative and quantitative methodologies to examine decision-making about inclusion and exclusion of children in their healthcare choices. A total of 52 interviews were carried out with physicians ($n = 16$), their patients ($n=17$), and the parents of these children ($n = 19$). The quantitative part included a prospective survey of parents and physicians. In this study, 36 interviews with parents and patients were analysed. A paper highlighting children's experiences with participation in their healthcare [22] and one on inclusion and exclusion of children in their healthcare is published elsewhere (Wangmo, de Clercq et al., accepted manuscript AJOB Empirical Research).

Study centres

The project was approved by the eight ethics committees in Switzerland, where data collection took place. Semistructured interviews were conducted in centres of the Swiss

Paediatric Oncology Group (SPOG). Four of the participating paediatric oncology units are set within university teaching hospitals and four are part of cantonal children's hospitals. Participating centres varied greatly in size: from 2000 to 2009, one centre had 58 new diagnoses, five had 100–200 new diagnoses, and each of the remaining three centres had about 400 new patients [23]. More recent data highlight that in the 5-year period between 2009 and 2013, a total of 1284 newly diagnosed cases were registered in all nine SPOG centres (no centre specific information given) [24].

Participant recruitment

Families were eligible for the study if a child between 9 and 17 years of age was diagnosed with cancer, and was receiving treatment at a participating SPOG centre. From an eligible family, one parent and the patient were recruited. Since the study tackles a sensitive issue, the research team in collaboration with participating centres decided that the treating oncologists should be the first to introduce the study to families. As the initial recruitment was not done by the research team, we cannot establish the exact number of refusals. It was also agreed that families would be approached for participation 3 weeks after diagnosis at the earliest, in order to give them time to process the news. Once the family expressed their wishes to be contacted, their information was sent to the interviewer, who contacted them. The child participant's consent to be interviewed was only sought after one of the parents had agreed to participate. A total of 21 families agreed to be contacted. Nineteen parents consented to participate in the study. We were unable to interview two parents due to language problems. Four of the 21 children declined to participate. The children's reasons for refusal included lack of interest in talking about this topic or not wanting to look back [22]. Written informed consent or assent was obtained from all participants and they were informed that participation was voluntary, they could withdraw anytime, and that the information they share would not be discussed with the physician. Children and parents were interviewed separately. Children were offered the possibility to have an oncology nurse or psycho-oncologist present if they felt uncomfortable talking to the interviewer alone. This option was chosen by one participating child.

Qualitative interviews

A semistructured interview guide was developed that included open-ended questions surrounding time of diagnosis, treatment, and opinions on participation in healthcare. For instance, concerning time of diagnosis, questions such as how they were told about the diagnosis, who told them, who was present, what discussions took place, and how they felt about these discussions, were posed. Relevant for this paper, they were also asked what they appreciated and what they did not regarding communication, decisions that were made and the general quality of care that they received, and what they would like to change. Both the parents and the children were asked similar questions, but the language was adapted to the child's understanding. Interviews with children lasted approximately 15 to 40 minutes (with the exception of one interview that lasted ap-

proximately 90 minutes) whereas interviews with parents lasted between 30 and 60 minutes. Recorded interviews were transcribed verbatim and checked for accuracy. Interviews were conducted in German, French, Italian or English. Parents and children were given the choice of place for the interview; 30 were conducted at the hospital, 2 at a Ronald McDonald House, and another 4 at the family’s home. These interviews were carried out from September 2012 to May 2015. This time range between the first and last interviews is due to challenges associated with recruiting minor patients and their parents to discuss difficult experiences on cancer. The demographic information of the 17 children and the 19 parents are presented in table 1.

Data analysis

Analysis of all interviews for the larger project included multiple readings and initial analysis using open coding where we coded topics that participants talked about. This step was carried out by at least two members of the research team using software for qualitative data analysis (MAXQDA.11). This analysis and discussions with the research team led to the identification of several major themes: diagnosis information, prognosis information, medical communication, decision making, parents’ role in communication, and reasons for including/excluding children [22]. Satisfaction with care was not a major theme from our first level of analysis as it was embedded as sub-themes within several main themes. Additionally, during the interviews, participating physicians relayed a strong wish to understand how patients and parents felt about the quality of care that they received at the SPOG centres. Hence, the research team chose to report on the perception of the patients and their parents on the quality of care that they received, their satisfaction with the care, and what they did not appreciate or found difficult. The second level of analysis was thus geared towards this paper. One team member re-read all interviews and intuitively scrutinised them for content with regard to factors, actions and circumstances that participants reported resulting in being satisfied with healthcare (e.g., medical treatments, medical discussions with healthcare professionals, general quality of care provided by the healthcare team) as well as challenges that participants encountered when receiving treatment for cancer. She extracted all segments of text related to the topic, which were then further analysed. A new coding process began with assignment of themes and subthemes [25] under this overall topic of satisfaction with care. Thereafter, this analysis was presented for veri-

fication to another team member familiar with the data and the initial coding process. All transcripts were analysed in their original language and only those quotes chosen to best represent the voice of the participants were translated into English and checked by another author. Names given in the results section are pseudonyms and we refrained from indicating the diagnosis of the child to assure confidentiality.

Results

Satisfaction with care

Parents were more articulate about their satisfaction as well as challenges that they faced during their child’s diagnosis and treatment than participating children. Both parents and children mostly reported high satisfaction with the care they received at paediatric oncology centres. Ben’s mother reported, “We felt very much cared for. My husband, myself and my son felt the same. Ben will tell you the same: we were very well advised and taken care of.” Satisfaction with care from the perspectives of parents was related to factors such as caring healthcare personnel, quality of communication, and healthcare team going ‘the extra mile’ (table 2). Generally, children did not “complain” about the healthcare providers and their satisfactions and dissatisfactions are presented separately from the parents.

Caring healthcare personnel

Parents reported that the healthcare team was caring since they made sure that the family comprehended the medical information that was given and ensured that families’ burdens are as minimal as possible. Vincent’s mother stated, “I find, they were really great, they suggested several times if we wanted to stop for five minutes (diagnosis communication), digest everything a bit ... they did not throw it [information] on the table.” The healthcare personnel were thus perceived as responsive to the needs of the family and understood what the family were going through.

Table 2: Themes from the qualitative analysis.	
Themes	Subthemes
1. Satisfaction with care	(a) Caring healthcare personnel (b) Quality of communication (c) Going the ‘extra mile’
2. Hurdles	(a) Difficult communication (b) Treatment at another unit (c) Reproductive choices

Table 1: Participant demographics (n = 36).		
	Parents (n = 19)	Children (n = 17)
Age: mean (range)	44.7 years (33–52)	13.8 years (9–17)
Sex	4 fathers; 15 mothers	11 boys; 6 girls
Nationality	13 Swiss; 6 other	Diagnosis:
Marital status	12 married; 7 other	ICCC-I Leukemias: 5
Education	11 vocational training 6 university degree 2 other	ICCC-II Lymphomas: 4
		ICCC-III CNS and miscellaneous intracranial and intraspinal neoplasms: 2
		ICCC-VIII Malignant bone tumours: 2
		ICCC-IX Soft tissue and other extraosseous sarcomas: 3
		ICCC-XI Other malignant epithelial neoplasms and malignant melanomas: 1

CNS = central nervous system; ICCC = International Classification of Childhood Cancer

I must really say, the time, it was a difficult time but they [oncologists] they responded to our needs and made sure that everything was taken care of. (...) Serena's physician and also the other [health professionals], they see that we do not have to return to the hospital 17 times. They tried to consider our wishes as much as possible (Serena's mother).

Participating parents also stated that the healthcare staff's way of engaging with them at the same level and their relationship with the child was important. Hannah's father highlighted his satisfaction when the oncologists spoke and gave information in a respectful manner: "you don't have the feeling: I stand here (points high) and you are (points low). (...) it is a meeting on the same level. You don't have the feeling that you are [ignorant], which I find very positive."

Quality of communication

Satisfaction was underscored by the quality of communication. Participating parents reported appreciating when physicians and other staff members communicated clearly and openly. They also revealed their satisfaction with medical communication when explanations were given in a manner that they were able to grasp. Information that was not adapted to their level of understanding led to dissatisfaction (discussed later).

We had a physician who can explain technical terms in a way that I as a layperson can understand and we had another physician who spoke more to Cristiano (...). When I see him, I absorb everything (that he says), like a sponge. (...) And he responds: You are always welcome to ask questions. (Christiano's mother)

Furthermore, parents highly valued the sheer accessibility to a contact person that was willing to answer their questions and provide clarifications. It meant that they were not left alone and had someone supporting them at all times.

Then the medical team is also [always available], you can always call them and ask questions. It was perfect. (...) we can always ask questions concerning side effects, although you have asked about it already twice or three times ... they always give an honest answer (Sam's father).

Going the 'extra mile'

Another aspect that emerged as contributing to satisfaction was when parents had the impression that oncology staff members went 'the extra mile'. That is, they took the time and energy to arrange things in a way that was helpful for the family. This included making sure that the patient felt comfortable in the hospital setting, accommodating treatments so that the patient could have some level of normality, and being the familiar face when treatment was underway.

He [Cristiano] mostly has a single room. They [staff] always made sure to give him the one with the bathroom so that he does not have [to use the bathroom] on the corridor. (...) I think they did everything possible so that he feels well. They try to arrange things in a way that he can go home, even if it is only for three to four hours! (Cristiano's mother)

Hurdles in receiving satisfactory care

Despite being generally satisfied with the level of care provided by the healthcare staff members, parents talked about difficulties they faced when their child was receiving care for cancer. The difficulties were grouped into three hurdles. These concerned communication, having to seek treatment at another unit, and the burden of making choices concerning reproductive issues (table 2).

Difficult communication

While parents perceived good communication as a source of satisfaction, communication that did not meet their needs was a reason for discontent. Communication challenges included having to deal with multiple physicians involved in the care of their child and exchanges of diagnosis information that went on for too long. The latter was not preferred since parents stated that they were in their initial state of shock after knowing the diagnosis and in need of a respite before being able to absorb any other information.

Well, we did have discussions but I would have needed more [time]. Especially because, as a layperson, you are thrown into cold waters, you need a little more time, at some point I had to tell the physician: You need to stop, I cannot follow you anymore. (Jeremy's mother)

One family also reported that the physician left them with a difficult treatment decision that they could not make, which gave rise to feelings of personal overload. They felt pressured due to lack of discussions with the physician and by the setting of a tight deadline to make an uninformed choice.

And he told us that we had to decide what to do and give him the answer within one or two days (...) so, they left us with a decision that we were absolutely not equipped to make. You cannot leave such a decision (to forgo a procedure foreseen in the protocol) to a parent. (Charlie's mother)

With Switzerland being a multilingual country, another communication hurdle revealed by the parents pertained to problems with language. As it was not always possible for families to receive care in their home region, they reported facing a language barrier. This meant that they needed a translator to help them understand the information, or measures had to be taken to accommodate them within the general hospital rules.

There was the problem with the language, a big problem, that is something that really should be, facilitated a bit more (...) When there were very important discussions, there was a physician [who spoke their language] (...) or else you can ask for a translator (...) it is just that this is something that has to be organized, [which means that] you have to wait longer. This is really annoying and stressful. (Jessica's mother)

Treatment at another unit

The second problem that parents reported was shifting to another unit for treatment. For families, having to seek treatment or care at a unit different from the paediatric oncology unit represented a source of stress and discomfort because they had to leave their familiar surroundings. They mentioned that physicians on those units sometimes did not communicate with the responsible oncologist or decided to do things differently. Such actions alarmed parents and they described feeling disappointed, and even angry.

I was annoyed because there was another head of department in the intensive care unit, very dictatorial: "You are under my responsibility; I decided to administer the [antihistamine] first, before the chemo." I told her: "No, doctor [name of oncologist] said that we do not want to mask the symptoms (...)" (Mia's mother)

Here in the pediatric intensive care unit there was no place. The surgery [lung operation] took place at the adult intensive care ... So he was placed in an intensive station for adults. There was a huge difference. We did not hear a nice word in three days. He had really, he had indeed very bad pain and they did not take care of him properly and did things that we had not agreed to. (Cristiano's mother)

Reproductive choices

The third hurdle that parents identified was having to discuss the reproductive choices of their children. In a few cases where the patient was either nearing or already starting puberty before beginning the treatment, fertility preservation was discussed to safeguard against possible detrimental effects of the therapy. Parents described feeling overwhelmed by this topic as it meant that they had to talk about intimate details with their adolescent child while still in the midst of the recent cancer diagnosis. This was exacerbated by the fact that the parent of the same sex as the patient was not always present to lead this discussion.

We [mother and son] had to go to the women's clinic, whether you are still fertile afterwards and sperm preservation and so on ... (...) I felt overwhelmed and my husband was not there. (...) Yes, suddenly you are confronted with things (...) and you think: Okay, it would be better to do this with Dad and not Mum. But he was on a business trip and you cannot organise everything in next to no time. (Dillan's mother)

Children's perspectives on satisfaction and their suggestions

Similar to the participating parents, children described being very content with the care they received and appreciated the interpersonal skills of the staff members. That is, the staff members were competent, caring and took the time to understand the situation the child was going through. Nora (15 years) revealed, "I think they did a very good job. I am really satisfied ... all in all I found it really good. Everybody is very nice around here." Dillan (14 years) stated, "I was able to ask many questions repeatedly, whether it [treatment] should be done now and other things ... They always responded to these concerns!"

Another factor that children reported valuing was honest and comforting communication. Louisa (14 years) said, "Really, I like the physicians because they reassure us a lot. They are honest. They find the right words, and that is really good (...) the same is true for the nurses." Jeremy (15 years), appreciating the precise and truthful information provided, added:

The physician explained [the medical information] quite well. (...) They (healthcare team) explained it to me one by one. They never hid anything, and always told me everything how the treatment would happen.

Regarding medical communication, children negatively perceived communication that did not meet their needs and that was too long. Suggesting that medical communication should be shorter, Vincent (17 years) reported, "It [communication of diagnosis] was long, we did three hours ... it is brainwashing, it was really long, this is something that would need to be changed ... shorter." Another recommendation was receiving some forewarning so that there was time to understand and adapt, Louise (14 years) noted:

The only thing I would change is that I would prefer to know everything in advance (...) What I really did not like was that a certain moment, at the end of the day, they came to me telling me that they would operate me the next morning. That is something I do not like, I really don't. (...) I did not have the time to adapt myself.

The other suggestions that children had were practical things that would have improved their stay at the hospital and, thus, aspects that they disliked. They mentioned that they disliked the particular smell of the disinfectants used in the hospital, hospital food and the lack of age-appropriate video games. Dillan (14 years) "Regarding the consoles here, it is rather oriented towards the younger children than towards the older ones. There are probably two games that still could be played by older children (...) I don't find it much appealing."

Discussion

The findings from this qualitative interview study with 36 participants are informative and noteworthy because in a

busy clinical setting, there is often little time left to provide feedback to the medical team. This paper brings forth the feedback of families concerning the quality of care that they received. In order to receive unbiased comments, it is of significant value to ensure such feedback is provided to an independent person outside the medical team. This was the case with our study, where the patients and their parents had the chance to state their opinions and experiences without it affecting their relationship with the medical team. In light of the numerous strains a cancer diagnosis of a child puts on the family [1] and the lack of research on satisfaction with care in paediatric oncology [16], the findings present concerns that should be addressed further with the goal of providing family-centred care of higher quality. The results from our study highlight children's and parents' overall satisfaction with care received at the Swiss paediatric oncology units. Factors associated with the satisfaction were interpersonal in nature [11–13], such as caring and committed staff members who sought to address every need of the patient and the family as much as they could and, at times, doing more than expected. Furthermore, the apt quality of communication that was in line with parents' and patients' needs and abilities also contributed to their overall satisfaction. Our findings support results from a survey study with young children (7–11 years) that revealed caring healthcare providers, trustworthiness, and communication as factors associated with satisfaction [26]. However, participants also reported situations that they perceived as inconvenient and discussed them in order to improve future quality of care for other patients and families.

First, communication was not always optimal and thus parents and patients reported that they sometimes received more information than they could understand and handle, particularly at the time of diagnosis, when everything is new, difficult and chaotic for the family. Similar findings are reported by parents who experienced receiving either too much or too little information [27]. Participants in our study valued having the possibility to ask questions any time and thus be able to gain and process information at their own speed. In this clinical setting, this may be a challenge as there often is a need to start treatment right away leaving little time for both children and parents to process information [8]. This concern demonstrates the importance of training physicians and other healthcare professionals in effectively communicating with parents and patients in this context [28].

Second, with four national languages, it is not surprising that a language barrier was viewed as a hurdle. This is an important issue for families that receive care outside their language region. The problem will be greater for families who do not speak one of the national languages or English, the working language of the Swiss Paediatric Oncology Group. Language problems may not only arise for Swiss nationals but also for foreign residents and immigrants or families from abroad seeking treatment in Switzerland. If parents or patients have the feeling that they do not understand or cannot adequately communicate with healthcare professionals, it can exacerbate the family's already difficult situation after receiving a child's cancer diagnosis.

Third, having to relate to another physician owing to change of shift was reported as a concern, as well as having to receive care from another unit. Although such changes are inherent in the organisation of a hospital and thus outside control, it may help healthcare professionals to keep in mind that such transitions can be a cause of worry for some families. Thus, emphasising that meticulous documentation is in place and that other healthcare personnel caring for the family will have access to it, that regular case conferences occur, and that close collaborative work with other units will take place may reassure parents there is continuity of care. As suggested by another study [29] access to medical information of the patient at the emergency department would be valuable.

Fourth, some aspects surrounding fertility preservation were reported as cumbersome. Such decisions for a minor child are extremely sensitive and have been found to be very important to both parents and adolescents [30]. It might be helpful for healthcare professionals to be aware that parents appreciate scheduling issues regarding fertility preservation some days in advance so that they can organise themselves and avoid feeling overwhelmed.

Finally, our child participants revealed several practical limitations such as food provided at the hospital and availability of leisure activities. These are practical areas that may be easy to adjust by the hospitals using a simple survey requesting concrete suggestions for improvements.

Future studies

Taking into account the results of this qualitative study, it will be valuable to conduct a bigger survey study in the paediatric oncology setting in order to assess patients' and parents' suggestions for improving hospitalisation experiences. Since these patients have long and frequent hospital stays, it is valuable for both patient satisfaction and good quality of care to assure attention to meet individual needs. Overall, more research is needed with regard to patient and parent satisfaction with care in paediatric oncology. While the majority of children with cancer will survive their disease [4] and these survivors are generally considered resilient, the illness and treatment experiences remain a risk factor for the development of psychological symptoms [31]. Satisfaction with care may be a factor influencing not only adherence to cancer treatment [14] but also compliance with follow-up care, which is considered increasingly important with regard to the high numbers of survivors in paediatric oncology who remain at risk for long-term adverse effects [32].

Limitations

Several limitations of the present study have to be noted. First, the interview data were not gathered with the main goal of gaining insight into parents' and patients' satisfaction when undergoing treatment for cancer. The themes reported in this paper came up during our analysis of the data. Hence, they may not be complete or thorough. Second, interviews were conducted in only German, French, Italian and English and thus the challenges of those families who mainly speak other languages are not represented. At the same time, participants of this study were selected by the treating oncologist and thus, they could be those with

whom physicians had a good relationship. Their experiences are not representative of all families seeking care in paediatric oncology settings in Switzerland. In light of the overall high level of satisfaction reported by parents and patients in this study, it seems important to take the small number of challenges that they mentioned seriously.

Conclusion

Patient and parent satisfaction is an important aspect of ensuring quality care that encompasses all aspects from medical to psychosocial issues throughout the illness trajectory. Even more importantly, such insights are valuable for improving healthcare to ensure that children with cancer and their families are optimally supported and guided throughout the difficult time they face when receiving the diagnosis and undergoing treatment. Medical personnel need to explore together with the families the level of information they can understand and deal with at a certain time, and they must be trained in carrying out such communication. With respect to language concerns that both Swiss and immigrant families face, we emphasise that being able to understand the exact details of the health condition is important for many aspects of treatment and adherence. Establishing structures that allow more immediate consultation of a translator or a healthcare professional who speaks the particular language can enhance families' experiences. In many units, such services may be in place informally but greater structural resources may be required to rapidly secure a translator for the language needed. Finally, access to medical information and clear communication between family and healthcare team as well as among the healthcare team within the oncology/haematology setting and other units where paediatric oncology patients may have to seek treatment is highly important.

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